



Davids, M. R., Caskey, F. J., Young, T., & Balbir Singh, G. K. (2017). Strengthening Renal Registries and ESRD Research in Africa. *Seminars in Nephrology*, 37(3), 211-223.  
<https://doi.org/10.1016/j.semnephrol.2017.02.002>

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[10.1016/j.semnephrol.2017.02.002](https://doi.org/10.1016/j.semnephrol.2017.02.002)

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# Strengthening renal registries and ESRD research in Africa

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## **Abstract**

In Africa the combination of non-communicable diseases, infectious diseases, exposure to environmental toxins and acute kidney injury related to trauma and childbirth are driving an epidemic of chronic kidney disease (CKD) and end-stage renal disease (ESRD). Good registry data can inform the planning of renal services and can be used to argue for better resource allocation, audit the delivery and quality of care, and monitor the impact of interventions. Few African countries have established renal registries and most have failed due to resource constraints.

In this paper we briefly review the burden of CKD and ESRD in Africa then consider the research questions which could be addressed by renal registries. We describe examples of the impact of registry data and summarise the sparse primary literature on country-wide renal replacement therapy (RRT) in African countries over the past 20 years. Finally, we highlight some initiatives and opportunities for strengthening research on ESRD and RRT in Africa. These include the establishment of the African Renal Registry and the availability of new areas for research. We also discuss capacity-building, collaboration, open access publication and the strengthening of local journals, all measures which may improve the quantity, visibility and impact of African research outputs.

**Keywords:** renal registry; translational research; open access; Africa; research impact

## **I. Introduction: Chronic kidney disease and end-stage renal disease in Africa**

The World Health Organization (WHO) estimates that around 60% of global deaths are due to non-communicable diseases (NCDs),<sup>1</sup> with most occurring in low- and middle-income countries (LMICs). Africa is a continent consisting of 54 low- and middle-income countries, home to a population of 1.17 billion people. Many of these countries are facing the triple burdens of infections, NCDs and injuries. There are insufficient studies on NCDs in Africa and there have been calls for more research to be conducted in this area.<sup>2, 3</sup> Based on the available evidence, NCDs are already responsible for more than three-quarters of deaths in most North African countries (Figure 1)<sup>4</sup> and while communicable diseases still predominate in sub-Saharan African regions, NCDs have been predicted to become the leading cause of death by 2030.<sup>5</sup>

[Figure 1 – Heat map of NCD deaths by country in Africa]

In LMICs, a disproportionate number of NCD deaths occur among younger people<sup>4</sup> who are at the peak of their economic productivity. This has serious economic consequences for families and communities. Healthcare costs for chronic diseases can drain household resources and result in the loss of breadwinners, thereby contributing to the persistence of poverty and the lack of economic growth in many African countries.

The World Health Assembly has endorsed the WHO Global Action Plan for the Prevention and Control of NCDs 2013-2020<sup>6</sup>. The targets for this important initiative include a 25% reduction in premature mortality from NCDs by 2025. While kidney disease is not explicitly mentioned, the actions which are planned have the potential to make a significant impact on the burden of chronic kidney disease (CKD). The modifiable risk factors for NCDs which will be targeted are tobacco use, physical inactivity, unhealthy diet (including the reduction of salt intake) and the harmful use of alcohol. These behaviours are typically established during adolescence or young adulthood, and therefore interventions aimed at young people are especially important in Africa, which has the world's youngest population.

The NCD epidemics of diabetes and cardiovascular disease (CVD) are well known, but the associated epidemics of CKD and end-stage renal disease (ESRD) have not received similar attention. In Africa, the combination of large increases in NCDs, a high burden of infectious diseases, exposure to numerous environmental toxins and high rates of acute kidney injury (AKI) related to trauma and childbirth mean that the incidence of CKD and ESRD is likely to be at least as high as is reported elsewhere.<sup>7, 8</sup> Diabetic nephropathy is a leading cause of ESRD globally, and also in Africa<sup>9</sup>. The number of adults with diabetes in sub-Saharan African is projected to increase from 19.8 million in 2013 to 41.5 million in 2035.<sup>9, 10</sup> Other important risk factors for CKD in the African region include hypertension and infection-related renal disease. The number of people with HIV in sub-Saharan Africa exceeds 25 million<sup>11</sup> and this contributes greatly to CKD in this region.<sup>12</sup>

The worldwide prevalence of CKD in adults is approximately 10-13%<sup>13, 14</sup> but there is little published data from most African countries.<sup>12, 15, 16</sup> A recent systematic review<sup>12</sup> highlighted the need for more studies of good quality from African countries. Based on 18 medium-quality and three high-quality studies the population prevalence of CKD in sub-Saharan Africa was estimated at 13.9%.<sup>12</sup> This estimate summarises data on 44 145 individuals from 13 countries. However, these crude prevalence rates mask a higher rate of CKD in African countries. For example, when the age distribution of the populations is taken into account ([www.wdi.worldbank.org](http://www.wdi.worldbank.org)), the crude prevalence of CKD in South Africa would be expected to be only two thirds that of the UK if it had the same population age distribution.

[Figure 2 – Population pyramid for Africa]

About 360 million Africans are between the ages of 10 and 24 (Figure 2).<sup>4</sup> By 2050, they will have aged and, if they develop NCDs at the current rate, this will place a huge additional burden onto poorly-resourced health systems.

The most serious sequelae of CKD are heart disease, stroke and progressive loss of renal function with development of ESRD. Again, there is a dearth of good data from most African countries. The annual incidence of ESRD in North African countries has been estimated at 150 per million population (pmp).<sup>17, 18</sup> Anand et al.<sup>19</sup> have modelled the incidence of ESRD in

developing regions and predicted an annual incidence of 239 pmp in people with diabetes and hypertension living in sub-Saharan Africa.

Renal replacement therapy (RRT) in the form of dialysis or transplantation is the treatment for ESRD. In most countries, especially LMICs, the incidence of RRT will not be the same as the incidence of ESRD, as it is a composite of both the disease rate and the access that affected people have to dialysis and transplantation services. Another measure that is important to consider is the number of people alive on RRT at any one point in time, the RRT prevalence, as this reflects the current human and economic burden of RRT on a society. Like RRT incidence, this is driven by the national burden of the disease and access to treatment (now and historically). It is also greatly affected by the survival rates on RRT. This effect of mortality is particularly relevant in low and middle income countries where chronic dialysis will be unaffordable to the majority and access to transplantation is limited.<sup>20</sup>

The lack of renal registries and related publications means that there are very few reliable, current statistics on RRT in Africa. Published estimates are often based on old registry reports and unpublished data<sup>15, 21</sup> but they do suggest that the provision of RRT services has been a low priority for the governments of most African countries. The prevalence of RRT is strongly associated with gross national income per capita.<sup>7</sup> Most African patients with ESRD are unable to access RRT and are treated conservatively. Liyanage et al.<sup>22</sup> estimate that there are at least 432 000 people in Africa requiring RRT but not receiving it. Where services are available, patients and their families generally pay out of pocket and most are unable to afford dialysis treatment beyond the first few months.<sup>23</sup>

Against this background, we consider which questions can be answered by national renal registries. We then summarise the existing research outputs from African renal registries and highlight some initiatives and opportunities for strengthening research on ESRD and RRT in Africa.

## **II. Which questions can be answered by renal registries?**

Renal registries collect a well-defined set of health and demographic data from patients on RRT over many years with the aim of generating information on the causes and incidence of ESRD, and information on the prevalence, treatment and outcomes of patients on RRT. A minimum dataset would include information on the numbers of patients on each treatment modality, the numbers starting or ending treatment each year, and basic demographic information on each patient. Most registries will report data at least annually, providing a snapshot of RRT in a country or region as at 31 December of each year.

In Africa, published registry data could be used to improve awareness of the as yet under-appreciated epidemic of CKD/ESRD and would provide critical information to support the planning, delivery and evaluation of renal services. Discrepancies in the provision of services within and between countries could be highlighted and this may encourage governments to allocate more resources for the treatment of ESRD.<sup>24</sup> Registry data can also aid in identifying the most important causes of renal disease in each country and thereby guide efforts to prevent, detect and treat the earlier stages of CKD. Table 1 summarises the questions that might be readily answered using data collected by renal registries.

[Table 1. Questions that can be addressed by renal registries.]

## **III. The impact of renal registries**

Registries have a key role to play in improving the health of populations, from identifying sub-groups with reduced access to treatment or poor outcomes, to monitoring the adoption and impact of evidence-based interventions. This role can be encapsulated in the term “translational public health research” (Figure 3) and is something registries have been doing to differing degrees for years, and in some instances with great impact. In this section, we provide selected examples of the impact of renal registries in African countries and beyond.

[Figure 3 - Translational public health research applied to renal registries, adapted from reference <sup>25</sup>.]

Tunisia: Since its establishment in 1990<sup>24</sup> the Tunisian dialysis registry has influenced decisions to increase the number of nephrologists, develop a new transplant programme, start new dialysis units and develop a kidney disease prevention programme. The rate of new patients starting RRT in Tunisia increased from 82 per million population (pmp) in 1992-1993 to 159 pmp in 2000-2001 and remains around this level.<sup>26</sup> Of note, the registry data was able to identify three regions reporting particularly low treatment rates in the elderly, which may have reflected regional obstacles to treatment.<sup>24</sup>

South Africa: The first report of the newly established South African Renal Registry was published in 2014 (December 2012 data),<sup>27</sup> nearly 20 years after the previous SA Dialysis and Transplant Registry was last published. The report revealed a markedly uneven distribution of RRT across provinces and large differences in RRT rates between the public and private healthcare sectors (73 vs. 620 pmp). The release of the report attracted prominent media coverage<sup>28</sup> and led to the national health minister convening a national summit on *“An effective approach to chronic kidney disease in South Africa”* in March 2015. It is hoped that a comprehensive approach and more resources will eventually flow from this initiative.

Thailand: In Thailand, data from the Thai Renal Registry was instrumental in building the case for the *“PD First”* programme<sup>29</sup> which, from 2008, saw a marked increase in access to peritoneal dialysis as the initial modality of treatment under their national healthcare insurance, Universal Coverage. Such rapid expansion in a country with areas of considerable poverty could have led to unintended negative consequences for some patients, so it was important that the Registry could provide essential quality assurance data on peritonitis rates and PD technique survival.<sup>30</sup>

Malaysia: Established in the early 1990s, the National Renal Registry of the Malaysian Society of Nephrology ([www.msn.org.my](http://www.msn.org.my)) is another very impressive renal registry. In addition to the basic data on treatment rates and modality, they report annually on the



attainment of quality standards, patient reported outcomes and renal biopsy data. They also provide an excellent example of how registry data was used to argue for increased funding of RRT as their country's national wealth increased.<sup>31</sup>

South America: The Latin American Dialysis and Transplant Registry has demonstrated that it is possible to establish and maintain a continental renal registry in difficult economic conditions.<sup>32</sup> Established in the early 1990s, this pan-Latin American partnership has contributed to the development of national registries and allowed countries to report their treatment rates and outcomes in the context of geographically, culturally and economically similar neighbours, challenging treatment modality preferences and highlighting the importance of primary and secondary prevention in CKD.<sup>32</sup>

Other examples: While there are many examples of renal registries delivering health improvements in high income countries, two are particularly noteworthy.

The DOPPS Practice Monitor: This initiative in the USA ([www.dopps.org/dpm](http://www.dopps.org/dpm)) provides rich insights into trends in care delivery by using a sampling approach to study secondary outcomes and without collecting data on every patient in every dialysis unit. Topics like vascular access, bone mineral disorder and blood transfusion rates have been the focus of specific reports.<sup>33-35</sup>

UK Renal Registry: It is becoming increasingly possible to use registries to provide the follow up for interventional studies and randomised controlled trials, an approach known as “efficient study design”. In the UK the effectiveness of a laboratory-level intervention that flags people with declining kidney function to prompt referral to a nephrologist is being evaluated. The outcome measure, percentage of patients presenting late to a nephrologist, has been routinely collected by the UK Renal Registry for years, giving robust baseline trend data and increasing power. Such registry-based pragmatic trials enable evidence to be gathered on the impact of new complex interventions. In a similar way, the UK Renal Registry is beginning to work with clinical trials units to design and deliver efficient individual-level randomised trials.<sup>25</sup>

#### IV. African renal registries: registry reports and related publications

A few renal registries, the majority from North Africa, have been established in African countries. Reports have not been published regularly. The earliest reports are from Egypt and Tunisia in 1975, followed by South Africa in 1977, and thereafter by Libya, Algeria and Morocco.

**North African registries:** The Egyptian Renal Registry first reported data from 1996<sup>36</sup> and the last reported data is from 2008.<sup>37</sup> The Tunisian registry, established in 1990,<sup>24</sup> was located in the Ministry of Public Health and achieved 100% coverage as the registration of patients was linked to reimbursement. However, the registry stopped functioning after 2011. In Morocco, the Moroccan Registry for End-stage Renal Disease (Magredial, <http://www.nephro-maroc.org>) was established in 2006 by the Ministry of Health in collaboration with the Moroccan Society of Nephrology and the Agence de Biomédecine. Its first and only report was published in 2008.<sup>38</sup>

**Other African registries:** The Nigerian Renal Registry was conceived 20 years ago but the use of complex questionnaires limited participation. A simplified version was introduced in 2014 and data from a few participating centres was presented at the 2015 Nigerian Association of Nephrology meeting (F Arogundade, personal communication). The South African Dialysis and Transplant Registry, established in 1977, stopped functioning due to lack of resources after reporting 1994 data. It has been re-established as the South African Renal Registry (<http://www.sa-renalsociety.org/registry.asp>), with its first report providing an analysis of 2012 data on RRT across the country.<sup>27</sup>

Table 2 summarises the African publications since 1996 which have reported national data on ESRD treated with RRT. Registry reports and other primary research publications reporting country-wide data have been included.

[Table 2. African publications reporting national data on RRT over the last 2 decades.]

In addition, there are published reports from regions or districts within a country such as those from Egypt<sup>39, 40</sup> and Algeria.<sup>41</sup> Data from North African countries have also been published in the ERA-EDTA Registry Annual Reports over a number of years (Table 3). Note that the 2014 Tunisian data describes the Sfax region only.

[Table 3. Contributions of data to the ERA-EDTA Registry by North African countries.]

## **V. Initiatives and opportunities for strengthening research on ESRD and RRT in Africa**

This section touches on a number of issues which have the potential for strengthening research and publication in the area of ESRD and RRT in Africa.

### **i. Establishing national renal registries**

Establishing a national renal registry is a vital first step for every country which offers maintenance dialysis and transplantation. In several African countries nephrologists have established renal registries but most of these efforts have not been sustainable, mostly because of resource constraints.

#### The African Renal Registry initiative

Recognising the need for renal registries in many African countries, the African Association of Nephrology (AFRAN) and the African Paediatric Nephrology Association (AFPNA) have now embarked on the establishment of a continental “African Renal Registry”.<sup>42</sup> At the World Congress of Nephrology in Cape Town in March 2015, AFRAN and AFPNA formally established the African Renal Registry which will utilize the Web-based platform of the

South African Renal Registry. Participating countries will share a stable, common technology platform and a common data dictionary which will facilitate joint analyses and comparisons between countries. Each country will retain full control over their own data and be free to report their country-specific findings. The Registry is currently being piloted in selected African countries.

Countries participating in the African Renal Registry are expected to obtain ethics approval, and preferably a waiver of individual consent. Registries that require individual informed consent achieve only partial enrolment and a good case can be made for obtaining waivers from institutional health research ethics committees so that individual consent does not have to be obtained.<sup>43</sup> As long as proper safeguards are in place to secure patient data, this risk can be balanced against the benefit of obtaining a more complete picture of ESRD and RRT in a country or region. The South African, UK, Scottish and French registries all operate using a waiver of consent.

## **ii. Improving research outputs**

Overall health research output in the WHO African Region has improved in recent years but remains at a low level, increasing from 0.7% of worldwide health research publications in 2000 to 1.3% in 2014.<sup>44</sup> National gross domestic product is an independent predictor of publication outputs. South Africa, Nigeria and Kenya contributed more than half of all the papers listed in Pubmed during this period but Gambia, Malawi and Guinea-Bissau were the leading countries when output was normalised for gross domestic product.<sup>44</sup>

### **Building capacity**

There have been many initiatives to improve research capacity in Africa. For example, the Initiative to Strengthen Health Research Capacity in Africa (ISHReCA) is an organisation of African health researchers formed in 2007 to strengthen Africa's capacity to carry out high quality health research and translate findings into policy and practice.<sup>45</sup> ISHReCA provides a

platform for discussion of health research needs and advocacy for governmental and societal support.

Of interest to researchers working with renal registries is that there has been a recent increase in epidemiological research productivity in the WHO/AFRO region. This is associated with the number of epidemiology programmes and the burden of HIV/AIDS in particular countries. More capacity building and training initiatives in epidemiology and biostatistics are required to advance research and address the public health challenges facing the continent.<sup>46</sup> Initiatives like the Chronic Disease Initiative in Africa and the Collaboration for Evidence based Health in Africa are putting dedicated investment into advancing capacity development and the conduct of relevant research on NCDs in Africa. Dedicated efforts are also continuing to develop biostatistics capacity for research.<sup>47</sup>

### Developing effective collaborations

Collaboration with high-income country (HIC) investigators and institutions can bring valuable expertise, funding, and other resources to Africa. However, much of the research is led, funded, and published by HIC researchers without equal collaboration from their African colleagues.<sup>48</sup> Data ownership is also often a contentious issue. Good partnerships address the priority health problems of a country or region and involve real capacity building. African researchers have to take an active role in directing these collaborations to set the research agenda, maximize the benefits and minimize the potential harm of these relationships.<sup>49</sup>

African researchers collaborate most frequently with partners in the USA (39,292 research papers in Web of Science between 2000 and 2012), France (31,421), the UK (25,753), Germany (13,879) and Canada (7,604).<sup>50</sup> Research collaboration between different African countries is poor. A study of collaboration among the 15 countries of the Southern African Development Community (SADC) and between the SADC and the rest of Africa found that only 3% of SADC papers during 2005-2008 were jointly authored by researchers from two or more SADC countries, and only 5% of papers were jointly authored with researchers from African countries outside the SADC.<sup>51</sup> Similar findings were reported from West African

countries, who also cooperated less with each other and with other African countries than they did with developed ones.<sup>52</sup> Collaboration between researchers from different African countries must be pursued vigorously as it is likely to result in improvements in both the quantity and quality of research.

The recent establishment of the African Renal Registry presents a new opportunity for collaboration between different African countries. Joint analyses and reporting is facilitated by the use of a shared IT platform and a common data dictionary.<sup>42</sup> Another initiative which may foster collaboration is the establishment of the East African Kidney Institute at the University of Nairobi (<http://chs.uonbi.ac.ke/node/9408>). The Institute was conceived as a centre of excellence for training and research, and actively seeks mutually beneficial collaborations. It is supported by the government of Kenya and the African Development Bank.

### Access to the research literature

Various initiatives have improved the access to research information for African researchers. HINARI (Health Internetwork Access to Research Initiative, [www.healthinternetwork.org](http://www.healthinternetwork.org)) is a partnership between the World Health Organization and scientific publishers which provides access to up to 13000 journals and 47000 e-books for institutions in more than 100 low-income countries.<sup>53</sup>

The International Network for the Availability of Scientific Publication (INASP) is an NGO working with a network of partners to improve access and use of research information.<sup>54</sup> INASP has facilitated access via the Programme for the Enhancement of Research Information (PERI) and the Strengthening Research and Knowledge Systems (SRKS, <http://www.inasp.info/en/work/what-we-do/programmes/srks/>) programmes, provided training for librarians, and supported the visibility of African research through the Journals Online (<http://www.inasp.info/en/work/journals-online/>) and African Journals Online (<http://www.ajol.info/>) platforms. Other initiatives include JSTOR (<http://www.jstor.org/>), the digital library which provides free or low cost access to over 1500 institutions in Africa

and other developing countries, and the Directory of Open Access Journals (DOAJ, <https://doaj.org/>).

The Arcadia report<sup>55</sup> explored researchers' access to scholarly materials at universities in east and southern Africa and found that the provision of online resources approached that of major European universities although affordability remained a challenge. The report recommended improved promotion of available resources and skills development for end-users.<sup>55</sup>

Internet access is critical in accessing these electronic resources and continues to improve, notably with the installation of high-speed undersea fibre-optic cables and the growing availability of mobile broadband.<sup>56</sup>

### New research opportunities

**Setting research priorities:** The global imbalance of research funding was recognised in the 1990s, when 90% of biomedical research funds were being spent on 10% of the disease burden.<sup>57</sup> Despite some progress, this marked disparity persists<sup>58</sup> and a systematic priority setting approach is required to address this. One of the case studies of the Essential National Health Research initiative was South Africa, which identified priority disease areas that are frequently associated with kidney disease (trauma, HIV, diarrhoeal illnesses and malaria).<sup>59</sup> Two of the characteristics for priority setting are best delivered by registries – “continuous burden of disease analysis” and “indicators of performance to track impact” – highlighting the key role of registries in translational public health research. The report also highlights the importance of priorities being “user driven” and including participants from all sectors.<sup>59</sup> There are now several examples, mainly from high-income countries, of the views of people with kidney disease being included in the setting of kidney research priorities.<sup>60</sup> African researchers should conduct similar studies as it is likely that the issues facing people with kidney disease in low- and middle-income countries will be situation-specific.

**Research synthesis:** In Africa, especially, the scarce resources for health research must be optimally utilised. Before embarking on new research, robust synthesis of relevant existing

research should be done to identify areas where new evidence is needed.<sup>61</sup> This is an essential step to avoid wasteful duplication and to reverse the trend of conducting and publishing small, low-impact studies. Key research priorities can be delineated through the combination of using systematic reviews and engaging with stakeholders. The recognition of the importance of research synthesis is reflected in the increasing calls for funding agencies to provide resources for conducting systematic reviews of existing research relevant to the developing world, as a scientific and ethical requirement, before investing in new research.<sup>61, 62</sup>

**Knowledge translation:** Promotion of the use of research to inform policy and practice is integral to the advancement of evidence based practices. A lot of research is available on strategies to promote the use of research in decision making<sup>63</sup> and policymakers and researchers need to draw on this to ensure better health outcomes. Integral to these strategies is timely production of relevant research, access to research, engagement between decision makers and researchers, and collaboration.

**Genetic studies and the H3Africa project:** The H3Africa Kidney Disease Research Network is a large initiative to study chronic kidney disease in sub-Saharan Africa and has a very strong focus on increasing the capacity for genetics and genomics research among African scientists. The network is part of the Human Heredity and Health in Africa Consortium (<http://h3africa.org/>) and is recruiting patients in Ghana, Nigeria, Ethiopia, and Kenya, and analysing environmental and genetic factors associated with CKD. It is envisaged that 4000 participants with CKD and 4000 controls will be recruited, as well as 50 families with hereditary glomerular disease.<sup>64, 65</sup> The capacity-building goals of this ambitious project are already being realised: 5 doctors have completed a 2-year training program on clinical research methods and biostatistics, 5 biomedical scientists are training in laboratory genomics, 1 masters-level student is training in biochemistry, 3 scientists are training in bioinformatics, and 2 research administrators are training in programme management.<sup>65</sup>

**Geographic information systems:** The “geographic approach” integrates geographic information into problem solving. Geographic information systems (GIS) can be used for modelling and mapping disease, predicting future disease risks and analysing the



distribution of resources and services. ESRD and RRT are uniquely suited to analysis by geographic methods as patients require expensive care in specialized facilities by highly skilled personnel. The distribution of new cases could identify high prevalence “hotspots” which could guide efforts to identify and address risk factors. There may be inadequate numbers or maldistribution of healthcare professionals, and long travelling times to dialysis facilities may compromise quality of life and clinical outcomes. GIS approaches can be applied to study the interplay between ethnicity, poverty, rural residence and access to RRT. Mismatching between resources and the patient population needs can be identified and interventions appropriately targeted.<sup>66</sup>

To establish whether African researchers are employing GIS approaches to studying renal disease in Africa we conducted searches (in July 2016) of Scopus, EbscoHost Academic Premier and Web of Science using the search strings (GIS OR geographic\* information system\* OR global positioning system\*) AND (kidney OR renal OR nephro\*). The search yielded no studies in the area of nephrology from Africa which have employed a geographic approach.

### **iii. Ensuring better visibility for African research, and strengthening African medical journals**

Existing African research is poorly visible and under-represented in international databases. In this section we consider what African researchers and African medical journals can do to improve the visibility and potential impact of their research.

#### **Publish ESRD/RRT data in peer-reviewed journals and embrace open access science**

**Publish in peer-reviewed journals:** Registry data, whether country-wide or regional, should be reported in peer-reviewed journals to ensure wide dissemination and increase the discoverability of the research. Data which lies only within registry reports (and not in medical journals) can easily be missed and therefore not have the desired impact.

**Embrace open access publication:** "Open access" (OA) refers to unrestricted online access to research publications, removing price barriers and most licensing restrictions. A recent review<sup>67</sup> demonstrated the positive correlation between OA publication and citations, scientific impact, media coverage, potential collaborators, job opportunities, and funding opportunities. By publishing their research as OA articles, African researchers are more likely to have their work discovered and cited. Other actions which can easily be taken to increase the visibility and impact of their work include depositing copies of published articles and preprints of new manuscripts in a public repository, sharing datasets, and pre-registering clinical trials in a registry such as the Pan African Clinical Trials Registry (PACTR, <http://www.pactr.org/>).<sup>67</sup>

Many institutions still create pressure on researchers to publish in higher impact factor journals, which are often not open access. However, the limitations of journal-level metrics are increasingly being recognized and there are strong movements, like the San Francisco Declaration on Research Assessment (SF-DORA),<sup>68</sup> which recommend that such metrics not be used to evaluate research outputs. More importance is being placed on the use of article-level metrics such as the h-index<sup>69</sup> and alternative metrics based on the Social Web (altmetrics). Altmetrics like Tweets, article downloads, mentions on blogs, and media articles have helped to demonstrate the impact of open access publication.

To date (July 2016) 46 African institutions have signed the Berlin Declaration on Open Access to Knowledge in the Sciences and Humanities, with Stellenbosch University the first African signatory in 2010.

### Strengthening African medical journals

The current availability of robust open source platforms for publishing scholarly journals has greatly reduced the barriers to establishing and successfully operating a medical journal. The Open Journal Systems (OJS) and SciELO initiatives are of particular relevance for African journal editors. There are three nephrology journals based in Africa and these are briefly described in Table 4. In addition, many papers are published in the Saudi Journal of Kidney

Diseases and Transplantation (<http://www.sjkdt.org>) by North African authors. The African nephrology journals all use OJS, either directly or via the AJOL platform.

[Table 4. African nephrology journals.]

**The Open Journal Systems platform:** Open Journal Systems (OJS, <http://pkp.sfu.ca>) is an open source initiative of the Public Knowledge Project at the University of British Columbia. OJS is a free online journal management and publishing system which seeks to improve the quality of journal publishing by supporting every stage of the publishing process, from online submissions through to reviewing, online publication and indexing. The Public Knowledge Project estimates that over 9000 journals were using OJS in 2015.

**Scientific Electronic Library Online (SciELO):** Since its inception in 1987 in Brazil, the online open access SciELO platform for scholarly publication has been implemented in 15 countries, mainly in South America. SciELO aims to improve the quality, visibility, use and impact of the included journals. The journals comply with strict quality criteria and appear on the Thomson Reuters Web of Knowledge platform as the SciELO Citation Index. SciELO South Africa (SA) became a full member of the SciELO Network Global Portal in 2012. There are currently 60 journals on the SciELO SA platform, including 17 health sciences journals.

**Using XML in the publishing process:** Extensible Markup Language (XML) is an “enabling technology” which improves the discoverability and accessibility of online research. XML tags the content of articles allowing publishers to use a single source file to create different formats of the same article such as PDF, html, ePub or print formats. The submission of XML metadata is also required by online vendors, who make articles searchable for a much bigger audience. For example, CrossRef ([www.crossref.org](http://www.crossref.org)) allows readers to access a paper that an article cites by clicking on the citation in the reference section. CrossRef does this by assigning each article a unique Digital Object Identifier (DOI) and linking this to the article’s XML metadata supplied by the publisher.<sup>70</sup>

**African Journal Partnership Program:** The African Journal Partnership Project (AJPP, <http://ajpp-online.org>) is another initiative which provides support for African journals. It is

sponsored by the US National Library of Medicine and the US Fogarty International Center, and partners African journals with leading US- and European-based journals.<sup>71</sup> Initially, African Health Sciences was paired with BMJ, Ghana Medical Journal with The Lancet, Malawi Medical Journal with JAMA, and Mali Médical with Environmental Health Perspectives and the American Journal of Public Health. There are currently nine African journals paired with six Northern partners. Since joining the project, participating journals have reported a sharp increase in the number of manuscripts received, lower acceptance rates and better overall quality in the research published.<sup>72</sup>

## Conclusions

It is clear that to be successful a renal registry must fulfil the needs of its key stakeholders. These needs will vary from country to country and may evolve over time, but they tend to begin with informing the planning of services and monitoring access to treatment then progressing to national audit and quality assurance. Studying disease and treatment rates for auditing and service planning involves elements of epidemiology, but there are many new exciting opportunities to utilise registry infrastructure to do research and efficiently generate new evidence on treatment effectiveness.

There are, of course, many challenges to setting up and maintaining a renal registry, even if all relevant stakeholders have been engaged. Sustainable adequate funding is crucial if the necessary infrastructure and expertise is to be established, developed and retained. African nephrologists have recognised the vital role that registries can play and, through the African Renal Registry and other initiatives, are seeking to create opportunities for efficiencies and synergies from working together to establish and run renal registries, and conduct research on ESRD in Africa. Through collaboration locally and globally registries have the potential to greatly improve the outcomes of people with kidney disease in all of our countries.

Annual reports and other scholarly outputs from renal registries need to be discoverable and accessible to have the greatest impact. In this regard, African nephrologists should

embrace open access publication and African editors should take advantage of the robust open source platforms which are available for establishing and operating medical journals.

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Table 1. Questions that can be addressed by renal registries. These can be related to (i) patients and their treatment and (ii) the resources available for RRT

<b>Patients, access to treatment, and outcomes</b>	
	Incidence and aetiology of acute kidney injury (biopsy-proven or clinically diagnosed)
	Dialysis therapy for - and outcomes of - acute kidney injury
	Incidence and prevalence of ESRD (or stage 5 CKD)
	Incidence and prevalence of patients accessing RRT
	Distribution of patients and disparities in their access to RRT <ul style="list-style-type: none"> <li>- age, sex, ethnicity, socio-economic status</li> <li>- geography – urban/rural, regional/provincial disparities</li> <li>- economic factors – medical insurance, access to private vs. public sector services</li> <li>- treatment modalities, including the use of transplantation, automated PD and home HD</li> <li>- access to medications such as erythropoietin, intravenous iron, immunosuppressives</li> </ul>
	Aetiology of ESRD
	Co-morbid diseases - especially diabetes, HIV, hepatitis B and hepatitis C
	Primary outcomes <ul style="list-style-type: none"> <li>- patient survival</li> <li>- modality/technique survival</li> </ul>
	Other commonly reported outcomes <ul style="list-style-type: none"> <li>- causes of death or reasons for cessation of treatment</li> <li>- hospitalizations</li> <li>- dialysis adequacy</li> <li>- vascular access in HD patients</li> <li>- laboratory data such as those related to anaemia management, bone-mineral disease, etc.</li> <li>- rejection episodes in transplant patients</li> </ul>
	Outcomes in sub-populations of interest <ul style="list-style-type: none"> <li>- children</li> <li>- the elderly</li> <li>- people with HIV</li> <li>- people treated conservatively, without RRT</li> </ul>
	Newer outcomes – the patient experience <ul style="list-style-type: none"> <li>- quality of life – both quantitative and qualitative data</li> <li>- employment</li> <li>- travelling issues and distances to units (using geographic information systems approaches)</li> </ul>
<b>Resources for RRT</b>	
	Human resources – nephrologists, renal nurses, dialysis technologists <ul style="list-style-type: none"> <li>- numbers, distribution and demographics</li> <li>- training, experience, formal qualifications</li> <li>- nature of their practice (clinical nephrology, teaching, research)</li> </ul>
	Physical infrastructure – dialysis units and transplant centres <ul style="list-style-type: none"> <li>- numbers, distribution, capacity, ownership, supervision</li> <li>- licensing authorities and licensing procedures</li> </ul>
	Technology and logistics <ul style="list-style-type: none"> <li>- availability of haemodiafiltration, automated PD, home HD</li> <li>- dialysis water treatment systems, water quality testing</li> <li>- maintenance and servicing of equipment</li> <li>- availability and distribution of PD fluid (locally produced or imported)</li> </ul>

	<p>Costs and funding of treatment</p> <ul style="list-style-type: none"> <li>- comparative costs of different modalities</li> <li>- government support and funding</li> <li>- funding from medical insurance, NGOs, other sources</li> <li>- costs borne by the patient and his/her family</li> </ul>
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Table 2. African publications reporting national registry data over the last 2 decades. Registry reports and other primary research publications reporting country-wide data have been included.

Author and year	Country/region	Last data	Journal article	Registry data reported	Publication type	Data reported	Comments
Afifi, 1999 <sup>36</sup>	Egypt	1996	Yes	Yes	Cross-sectional study	Prevalence, aetiology, mortality	First report by the Egyptian Society of Nephrology
Afifi, 2008 <sup>37</sup>	Egypt	2008	No	Yes	Registry report	Prevalence, aetiology, quality measures	Presentation, available as a PDF file
Masri, 2004 <sup>73</sup>	Egypt, Libya, Morocco, Sudan, Tunisia	2003	Yes	Yes	Transplant registry report	Transplant rates, donor types	Data from the Middle Eastern Society of Transplantation Registry
Alashek, 2011 <sup>74</sup>	Libya	2009	Yes	No	Cross-sectional study	Prevalence, treatment centres, HR	Detail on centres, staffing, infection control and quality measures
Alashek, 2012 <sup>75</sup>	Libya	2010	Yes	No	Cross-sectional study plus prospective arm	Incidence, prevalence, aetiology	Incidence established via 1-year prospective arm
Albitar, 1998 <sup>76</sup>	Reunion Island	1996	Yes	Yes	Registry report	Incidence, prevalence, aetiology, mortality	Data from the Indian Ocean Society of Nephrology registry
Davids, 2014 <sup>27</sup>	South Africa	2012	No	Yes	Registry report	Prevalence, aetiology, treatment centres	First report of a new national registry
Davids, 2015 <sup>77</sup>	South Africa	2013	No	Yes	Registry report	Prevalence, aetiology, treatment centres	
Davids, 2016 <sup>78</sup>	South Africa	2014	No	Yes	Registry report	Prevalence, aetiology, treatment centres	
Elhassan, 2007 <sup>79</sup>	Sudan	2007	Yes	No	Prospective cohort study	Incidence, complications, mortality, treatment centres, HR	First report of a new national PD programme
Elamin, 2010 <sup>80</sup>	Sudan	2009	Yes	No	Cross-sectional study	Prevalence, aetiology, treatment centres, quality measures	
Counil, 2008 <sup>24</sup>	Tunisia	2001	Yes	Yes	Observational study	Incidence, aetiology	An analysis of trends in incidence of RRT 1992-2001

Ben Maïz, 2010 <sup>81</sup>	Tunisia	2008	Yes	Yes	Review of nephrology in Tunisia	Incidence, prevalence, treatment centres, HR	
Ministry of Health, 2010 <sup>82</sup>	Tunisia	2010	No	Yes	Registry report	Prevalence, aetiology, mortality, treatment centres, HR	

Table 3. Contributions of data to the ERA-EDTA Registry by North African countries. The dates refer to the dates of data collection. From reference <sup>42</sup>.

Country	First and last data submissions		Comments
Algeria	1981	1997	No data submitted for 1994
Egypt	1975	1996	No data for 1978-80, 1994-5
Libya	1980	1996	No data for 1993-4
Morocco	1995	1997	
Tunisia	1975	2014	No data for 1978-80, 1994, 1998-2000, 2006, 2009-2013

Table 4. African nephrology journals. The publication frequency reflects the number of issues published in recent years.

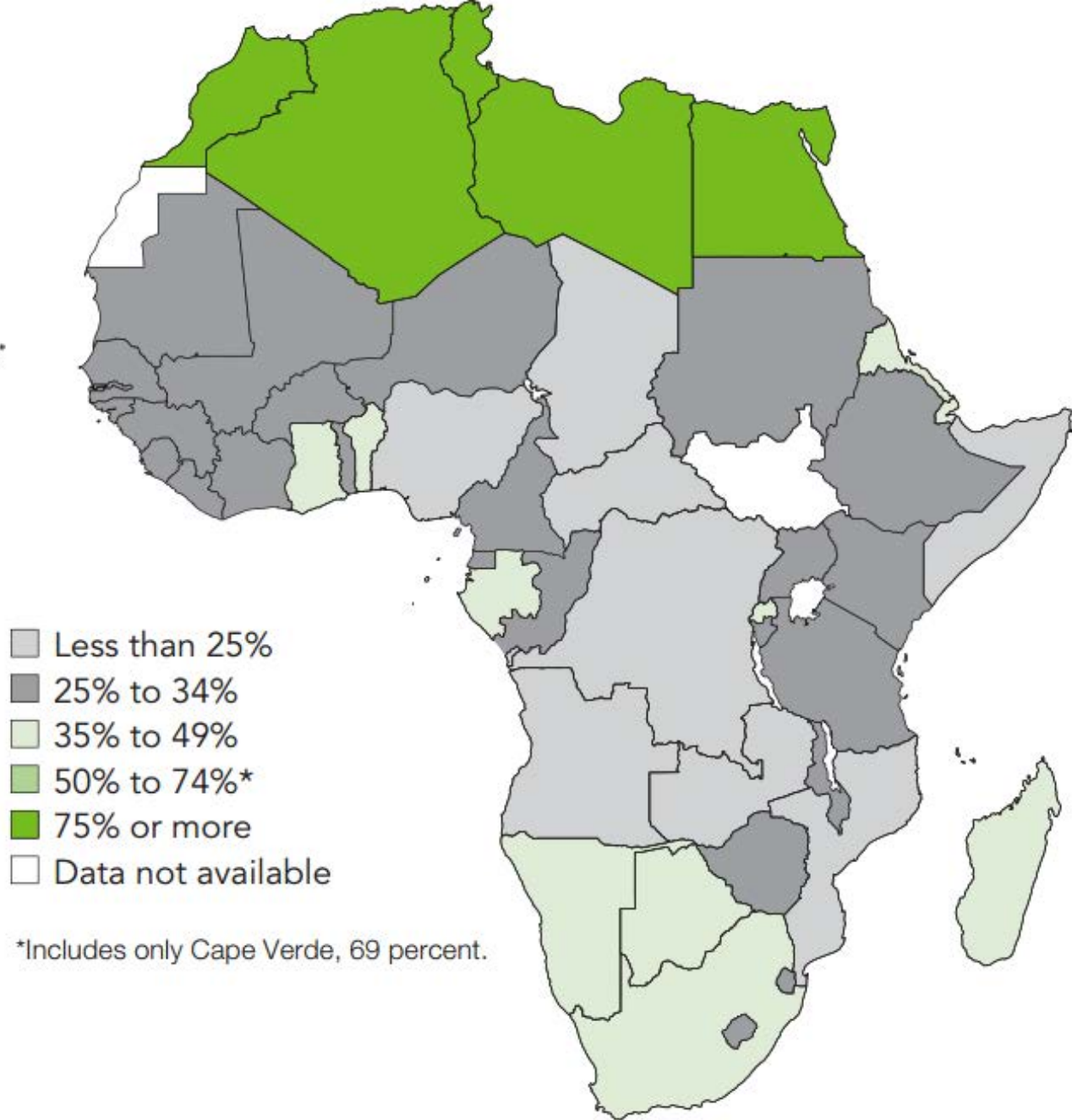
Journal name and website address	Start date	Open access	Issues per year	Notes
<b>African Journal of Nephrology</b> - <a href="http://www.journals.ac.za/index.php/ajn/index">http://www.journals.ac.za/index.php/ajn/index</a>				
	1997	Yes	1	Publication of the African Association of Nephrology
<b>Arab Journal of Nephrology and Transplantation</b> - <a href="http://www.ajol.info/index.php/ajnt/index">http://www.ajol.info/index.php/ajnt/index</a>				
	2008	Yes	3	Publication of the Arab Society of Nephrology and Renal Transplantation
<b>African Journal of Paediatric Nephrology</b> - <a href="http://www.ajol.info/index.php/ajpn/index">http://www.ajol.info/index.php/ajpn/index</a>				
	2014	No	2	Publication of the African Paediatric Nephrology Association

## Figures

Figure 1. Heat map of deaths due to noncommunicable diseases in Africa in 2012.<sup>4</sup>

Figure 2. Population pyramid for Africa.<sup>4</sup>

Figure 3. Translational public health research applied to renal registries. Red arrows indicate sites on the pathway where renal registries can contribute. R&D = research and development. Adapted from reference <sup>25</sup>.





# Population Pyramid, Africa: 2014 and 2050

## Population Size

2014 1,136 million

2050 2,428 million

